

NMF National Marfan Foundation

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April 30, 1998

The Honorable Thomas Daschle
Democratic Leader
509 Hart Senate Office Building
Washington, DC 20510

Dear Senator Daschle:

I want to commend you for your Patients Bill of Rights Act of 1998. It is sorely needed, as you know. We of the National Marfan Foundation particularly are aware of the need to be able to seek expert and qualified medical care outside the normal HMO and insurance network. It is also important that physicians not be penalized by the HMOs when the physicians serve as advocates for their patients. It should be self evident that health care professionals should be able to cooperate with government agencies in the investigation of substandard care without being penalized by the various HMO systems.

We would like to go on record as supporting the Patients Bill of Rights Act so that people with the Marfan syndrome and related disorders have the finest care available to them.

Thank you and do keep us informed as to the progress of this bill.

Sincerely,

Priscilla Ciccariello
Priscilla Ciccariello
Chair

PC/ct
encl.

Serving the Needs of People with the Marfan Syndrome and Related Connective Tissue Disorders

Affiliations:
National Organization of Rare Disorders, Alliance of Genetic Support Groups, National Voluntary Health Agencies, Coalition for Heritable Disorders of Connective Tissue,
International Marfan Association, Coalition of Patient Advocates for Skin Disease Research, Consortium on Rare Diseases